

**Testimony of Yvonne Brown
Individual Living with Multiple Sclerosis
Oversight and Government Reform Committee
U.S. House of Representatives
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Introduction

Thank you Chairman Waxman, and distinguished Members of the Committee, for inviting me to provide public testimony at this very important hearing. And thank you Chairman Waxman for your leadership on this issue.

I'm happy to be here today to speak on behalf of all people who live with multiple sclerosis or MS, and who struggle to pay for the very expensive treatments.

My name is Yvonne Brown. I live in Waldorf, Maryland. And I have MS. I am not a big pharmaceutical company. I am not a lobbyist. I'm simply a 44-year-old woman who struggles every day with the devastating effects of MS and I'm someone who cannot afford my medications.

First, let me tell you a little about what MS is and what MS does. Then, I'll share my personal story.

MS is a chronic, unpredictable, often-disabling disease of the central nervous system. Very simply, MS interrupts the flow of information between the brain and the body. It basically stops people from moving in one way or another. There is no cure.

MS can cause blurred vision, loss of balance, and poor coordination. It can cause slurred speech, tremors, numbness, and extreme fatigue. It also can cause problems with memory and concentration, paralysis, and complete blindness. These problems can be permanent, or they can come and go. It depends on the person.

Most people are diagnosed between the ages of 20 and 40. So for many people like me, it is a prime of life disease. Although individuals as young as 2 and as old as 75 have developed it. MS is not considered a fatal disease because the majority of people with it live a near-normal life span. But we struggle to live productive lives and face increasing limitations.

More than 400,000 Americans have MS, and every hour someone is newly diagnosed. World-wide, MS affects about 2.5 million people.

Like I said, there is no cure for MS. The National Multiple Sclerosis Society however, recommends treatment with one of the FDA-approved "disease-modifying" drugs as soon as possible following a diagnosis of MS. These drugs slow the progression of the disease and can help to lessen the frequency and severity of MS attacks. They can reduce the accumulation of lesions in the brain. And they can help slow the progression of disability.

In addition to drugs that address the basic disease, many people with MS take a number of additional medications for problems related to MS. They treat symptoms such as spasticity, depression, pain, bladder problems, fatigue, sexual dysfunction, weakness, and cognitive problems.

Unfortunately, the cost of treating MS is often financially devastating for the person with the disease and their family. I know this personally. Four of the six FDA-approved "disease modifying" drugs are considered biological drugs. The disease modifying drugs range from \$16,000 to \$25,000 a year — about twice the amount of Social Security disability I receive annually.

My Struggle

For me, MS is a struggle every day. But sometimes the financial struggle to get my treatment can be more troubling than this in-curable disease. I'm here today to appeal to this committee. I'm asking you to promptly provide a regulatory pathway for the Food and Drug Administration (FDA) to review and approve follow-on biological therapies. I'll share my personal story with you as an example of the immediate need for this legislation to become law.

Today is a good day actually. But it is not always good. In the past I have struggled a lot with my MS and with trying to get the prescriptions I need to feel a little better.

I was diagnosed with MS in April 2000 at 37 years old. In August 2000, I was prescribed Avonex, a biological drug produced by Biogen Idec. The cost of the Avonex is high and I struggled to do whatever I could to afford my prescribed therapy. I sold my computer. I disconnected my phone. I skipped paying a lot of my bills. I never could have imagined reaching that point. I was doing everything I could just to stay afloat.

Despite this, I lost my home before the end of 2001 and was living in my car. From 2001 to 2005, I was homeless. I lived in my car most nights and sometimes with friends. I struggled for years to get approved for Social Security during this time. And I tried for over 3 years to be approved for subsidized housing.

I was even turned down for help at shelters because of my MS diagnosis. Staff at shelters felt I was a health liability due to my problems with balance and frequent falls. I became accustomed during this time to begging, borrowing, and pleading for any help I could get so I could obtain treatment.

Unfortunately, during these years, my access to my prescribed treatment was sporadic and I paid the consequences with increased symptoms and more frequent attacks. It was a terrible cycle.

As a result of not having access to Avonex for an extended period of time, in 2004 I was hospitalized for 1 day and 1 night. The cost of my 24 hour stay in the hospital was nearly \$1,000. I am still trying to pay that bill.

Today, after finally being approved for Social Security disability, I receive \$1,100 a month and am covered under Medicare. I do have coverage for my medications but my co-payment is \$220 a month just for Avonex. When you only have \$1,100 a month to live on, \$220 might as well be \$220 million.

I don't want to be homeless or live in my car again, so I cannot miss rent. I don't want to risk my health so I cannot skip too many meals. I often skip paying bills but I cannot get too far behind or I risk losing my electric, water, or other vital service. And I do my best to pay my share to those who provide my treatments.

Because of this, even today, I must miss my treatments occasionally. There is simply nothing I can do sometimes. It is a choice between paying the rent and paying for my medication. And I am not the only one who struggles with this.

It is a misconception that help is readily available for people in situations like mine. It is true that various programs exist. However, those programs are often difficult to navigate, have varying qualifying criteria, take a long time, and sometimes actually run out of money. For example, last year I was finally approved for assistance by the National Organization for Rare Disorders. However, before I received any assistance, I was told by NORD that they ran out of funding. Again, I was stuck.

It is also possible to get assistance, sometimes, directly from Biogen Idec, the manufacturer of Avonex. However, that process too is fragmented and long. After asking Biogen for help over 1 year ago, I think I am close to getting some help with coverage during the Medicare Part D doughnut hole which I will already enter in April. I learned my lesson though and this time I know not to count my chickens before they hatch.

As a person with MS, I take many other prescription drugs including those for hypertension, depression, and several supplements. The difference with all my other drugs is that generics are available. This keeps my co-payments low and

manageable. Most importantly I do not have to miss these treatments because I cannot afford them. But this is not true for my MS therapies and never will be unless something changes.

Solution

As you can see, there is a problem. But hopefully you can help with a solution. I am a person with a chronic, life-long, costly disease. The cost for treating my MS alone is \$1,700 a month and I receive \$1,100 a month on Social Security. Thankfully, I do have some prescription drug coverage but I still have an unaffordable co-payment of \$220 a month – just for Avonex. Simply put, I cannot afford my treatments.

I want to stay out of a wheelchair and I want to stay out of a hospital. I want to contribute my talents to my community. I want to pay taxes. I am a volunteer and I want to stay healthy so I am able to help others who have MS.

I want to stay on my treatments. If I don't have access to my treatments, my health will continue to decline.

The stress from the story I've told you has caused me to begin to lose my hair. Frankly, I don't really care. I just want to battle this beast that is trying to take away my movement. And I want to fight for others who no longer have the strength or resources.

This is my own story, but it is not unique. Millions of Americans rely on biologic drugs for treatments of their diseases. Millions of Americans struggle terribly with those costs.

If I can leave this committee with one thought it is that no matter how good a drug is supposed to be, it has no chance of being effective if it is not affordable to those who need it. For a long time, no treatments were available for MS. Now there are. The sad thing is, it doesn't matter. Many people just can't afford them. They cost too much. And right now, there is no possibility that biologic MS therapies will ever be less expensive. For many like me, there is little hope in sight. We have to change that.

This legislation has the power to move us a little closer. I know there are a lot of other variables in this process. But we all know that providing more affordable medications for all Americans is a serious priority. For biologic MS therapies, we will never, ever reach that goal if we don't start by simply providing the pathway. It is a necessary first step.

I'm afraid that we have already missed the opportunity to make some drugs more affordable for those who need them most. But if we act now, there are many, many other people who can still be helped.

Thank you again for your invitation and attention. I hope you remember me, and people like me, as you consider this important legislation. Please help us provide more affordable biological drugs for those who desperately need them. Help provide a regulatory pathway for the Food and Drug Administration (FDA) to review and approve follow-on biological therapies. Thank you.